

Robertson, A. E., and Simmons, D. R. (2015) The sensory experiences of adults with autism spectrum disorder: a qualitative analysis. *Perception*, 44(5), pp. 569-586.

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Deposited on: 28 May 2015

The Sensory Experiences of Adults with Autism Spectrum Disorder: A Qualitative Analysis

Ashley E. Robertson and David R. Simmons

School of Psychology, University of Glasgow

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Abstract

It has been well-established that individuals with Autism Spectrum Disorder (ASD) report unusual experiences with sensory stimuli compared to typically developing individuals. However, there is a paucity of research exploring the nature of such experiences. A focus group was conducted with six adults with a diagnosis of autism or Asperger syndrome (AS). Data were coded and analysed using an inductive, qualitative thematic analysis. Four main themes encompassing both positive and negative sensory experiences emerged from these data a) the importance of particular aspects of stimuli in their perception, b) the importance of having control over stimuli, c) how emotions/mental states could impact/be impacted by sensory stimuli and d) physical responses to stimuli. These data are discussed alongside extant literature. Limitations, possible implications and potential directions of future research are also discussed.

Keywords: Autism Spectrum Disorders, sensory, qualitative, focus group

Author Note

Ashley E. Robertson and David R. Simmons, School of Psychology, University of Glasgow, UK.

Ashley E. Robertson is now at the Institute of Health and Wellbeing, University of Glasgow, UK.

This research was supported by an ESRC-CASE +3 studentship (funded in collaboration with Carers Link East Dunbartonshire), a University of Glasgow First Steps Award and an EPSRC-KTA grant. David R. Simmons was partially supported by a grant from ESRC (“Social interactions: A cognitive neurosciences approach” (RES-060-25-0010)). This paper was included as a chapter in Ashley Robertson’s doctoral thesis. We would like to thank the participants who took part in the focus group, as well as the staff member who acted as gate-keeper. We would like to thank Dr Fiona Mitchell and Emily Scott for their valuable comments on the manuscript, and Ciara Stiles for her input on the use of music with clinical populations.

Correspondence regarding this article should be addressed to Ashley E. Robertson, Research Institute of Health and Wellbeing, University of Glasgow, 1st Floor, Admin Building, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH, UK. Contact: ashleyerobertson@icloud.com

Introduction

Sensory issues are commonly reported in Autism Spectrum Disorders (ASD), from both first-hand (Grandin & Scariano, 1996; Jones, Quigney & Huws, 2003; Williams, 1998) and second-hand (Baranek, David, Poe, Stone & Watson, 2006; Leekam, Nieto, Libby, Wing & Gould, 2007; Dickie, Baranek, Schultz, Watson & McComish, 2009) perspectives. Examples of common sensory issues include hyper-reactivity to stimuli, including bright lights, loud noises and strong odours, as well hypo-reactivity to certain sensations (e.g. touch and sound). Moreover, there is evidence of unusual sensory responsiveness in individuals with high levels of autistic traits (Robertson & Simmons, 2013) and mothers of individuals with ASD (Uljarević, Prior & Leekam, 2014). Furthermore, there is experimental evidence that particular aspects of visual (Simmons et al., 2009), auditory (Haesen, Boets & Wagemans, 2010), gustatory (Tavassoli & Baron-Cohen, 2012), olfactory (Dudova et al., 2011), tactile (Cascio et al., 2008) and multisensory (Foxy et al., 2013) processing is different for people with ASD.

It is a particularly appropriate time to explore sensory experiences in this population, due to the recent changes to the diagnostic criteria for ASD. Within the previous version of the Diagnostic and Statistical Manual for Mental Disorders, (DSM-IV-TR: American Psychiatric Association, 2000), atypical sensory reactivity was viewed as an associated symptom of ASD. However, the latest version of the diagnostic criteria has been expanded to include hyper- and hypo-reactivity to sensory stimuli (DSM-5: American Psychiatric Association, 2013), including it as a subcategory under ‘restricted and repetitive behaviours’. This means that atypical sensory reactivity can contribute towards, but is not necessary for, a diagnosis to be made. This suggests that unusual sensory reactivity is an important aspect of ASD, and that future work to uncover the impact on individuals with ASD is necessary.

There are a number of neural theories of autism that aim to explain the unusual sensory processing reported within this population. Enhanced Perceptual Functioning theory (EPF: (Mottron, Dawson, Soulières, Hubert, & Burack, 2006) is based on the premise that individuals with ASD exhibit superior local processing abilities. This theory proposes that ASD stems from a superiority of low-level perception (such as discrimination and pattern perception), resulting in increased attention to lower-order cognitive processes, at the expense of higher-order ones (e.g. social interaction) (Mottron & Burack, 2001). In an update to the EPF theory, the authors hypothesised that the superior local processing observed in ASD is a result of mandatory global bias in individuals without ASD, even when it is detrimental to task performance (Mottron et al., 2006). The ‘neural noise hypothesis’ also provides an account for atypical sensory reactivity reported in ASD. The concept of a “noisy system” has been proposed in multiple studies and reviews (Dakin & Frith, 2005; Franklin et al., 2010; Sanchez-Marin & Padilla-Medina, 2008; Simmons et al., 2009) to explain the performance of individuals with ASD. When combined with the evidence of increased heterogeneity in ASD, particularly that of intra-participant variability (Milne, 2011), it was proposed that neural noise could account for the strengths and impairments observed in ASD (Simmons et al., 2007).

There appears to be a disparity between the results of parent-/self-report and behavioural studies, with the former finding consistent differences between the sensory responses of children with ASD and typically developing children (Baranek et al., 2006; Leekam et al., 2007; Ben-Sasson et al., 2009), as well as children with other clinical disorders (Rogers, Hepburn & Wehner, 2003, Baranek et al., 2006). However, despite differences in some aspects of sensory processing (Bertone, Mottron, Jelenic, & Faubert, 2005; Cascio et al., 2008; Shah & Frith, 1983) there do not appear to be differences in the visual contrast sensitivity (Bertone et al., 2005), visual acuity (Bölte et al., 2012) or absolute hearing (Khalifa

et al., 2004) thresholds of individuals with ASD and typically developing controls. One potential explanation for this is that people with ASD are not better able to sense stimuli *per se*; instead, they might process certain aspects of sensory stimuli differently to individuals without ASD. Indeed, it may be the case that some of the differences highlighted in self-/parent-report accounts may not yet be observable using current experimental paradigms.

There are many contrasts between qualitative and quantitative research, with each having its own advantages and disadvantages (Creswell & Plano Clark, 2011). Generally, a qualitative approach aims to gain an in-depth understanding of behaviour, and the reasons underlying it. In contrast, the quantitative methodology presupposes that there is a singular reality, and that cause and effect can be determined by using tightly controlled experiments (Creswell, 2003). A phenomenological approach is one type of qualitative methodology. It opines that there are multiple realities, and that by elucidating details of people's perception of various events, experiences and relationships, an understanding as to how these events are connected can be reached (Creswell, 2003). There are a number of advantages to this type of research. For example, it can enable researchers to develop a deep understanding of the lived experience of individuals and can also contribute to the development of new theories.

The first published study to utilise a qualitative approach to explore sensory processing in adults with ASD was conducted by Jones et al. (2003). They investigated self-published online accounts of five individuals who reported they had a diagnosis of high-functioning autism (HFA). Using Grounded Theory analysis (Corbin & Strauss, 2008), they found that four categories emerged from the data: turbulent sensory experiences, coping mechanisms, enjoyable sensory experiences and awareness of being different. More recently, Smith and Sharp (2013) used a modified version of Grounded Theory to explore unusual sensory experiences in adults with Asperger Syndrome (AS). They found that unusual sensory events were attributed to a reportedly heightened sensitivity to sensory stimuli, and that this could

result in either enjoyable or distressing experiences. Finally, Robledo, Donnellan, & Strandt-Conroy (2012) used the constant comparative approach (Charmaz, 2000, 2006) to examine sensory and movement differences from the perspective of adults with autism. They found strong support for the concept that a disruption of organisation and regulation may lead to sensory and movement experiences in autism that are amplified in their quantity, quality and intensity.

Researchers have also explored the sensory responsiveness of children with ASD from multiple perspectives. Dickie et al. (2009) investigated the sensory experiences of children with autism, from the perspective of their parents. Using the Critical Incident Technique (Flanagan, 1954), the authors found that parents of children with autism reported more extreme or unusual sensory experiences than parents of typically developing children. More recently, Kirby, Dickie, & Baranek (2014) held semi-structured interviews with children who had a diagnosis of ASD, for the purposes of gaining insight into their sensory experiences. The authors found that the children in their sample frequently characterised their sensory experiences (especially aversive ones) by the reaction they had to it. This was often framed as a *need* - for example, that they had no option but to cover their ears when they heard a loud noise.

A focus group is a group discussion that centres on a certain topic. Rather than being of a question and answer format, participants are encouraged to interact with each other on a focused topic. One benefit of focus groups over individual interviews is that participants query others in the group, as well as explain themselves to them (Morgan, 1996). In particular, such interaction allows the researcher to observe the extent of the consensus and disagreement between participants (Morgan & Kruegar, 1993). The aim of our study was to gain insight into the sensory experiences of individuals with ASD, in their own words, by utilizing a qualitative approach. This article reports, as far as we are aware, the first focus

group discussion of sensory issues in a group of high-functioning adults with a clinical diagnosis of ASD.

Methods

Participants and Recruitment

Six adults (one female; five males) with a diagnosis of autism or Asperger's syndrome (AS) were recruited to this study. All participants were highly able, articulate and worked for a local company that employed adults with ASD. The research team did not independently confirm diagnoses, but all employees were required to have a clinical diagnosis of autism or Asperger's syndrome (i.e., obtained from a psychiatrist or clinical psychologist) in order to gain employment with this company, unless they were in a managerial or support role. All participants knew each other prior to the focus group, although some had only recently joined the company. Participants were aged between 24 years 2.5 months and 51 years 6.3 months at the time of the focus group (mean = 32 years 1.3 months; SD = 10 years 3.1 months).

Procedure

This study was organised through a gate-keeper already known to the participants, who scheduled the focus group at a time convenient to everyone involved. The focus group took 1 hour 20 minutes to complete, excluding a 20 minute break at an appropriate point in the discussion. All participants were fully informed about the study prior to recruitment, although the researcher re-iterated the most important points and answered any questions prior to starting the group. All participants also signed consent forms and filled out a brief demographics questionnaire. The topic of the focus group was sensory issues in autism spectrum disorders. The researcher's role was to moderate the group, ensuring that people were given ample opportunity to speak and that the discussion remained on-topic. The discussion was audio-recorded and transcribed, with the data being analysed using an

inductive approach. Three months after the focus group had taken place, participants were emailed a two-page summary of the results.

Key questions for the focus group

Questions and prompts were prepared prior to the focus group. The key questions were formulated based on two theories of perception in autism as well as impacted by previous research. The Enhanced Perceptual Functioning Theory (EPF; Mottron, Dawson, Soulières, Hubert, & Burack, 2006) and neural noise hypothesis (see Dakin & Frith, 2005 and Simmons et al., 2009 for reviews) discuss the existence of atypical sensory reactivity in ASD. The purpose of Q1 was to explore the hyper- and hypo-reactivity to sensory stimuli discussed in these theories. The rest of the questions were constructed based on previous research we had conducted in the area (e.g., Robertson & Simmons, 2011; Robertson & Simmons, 2015). We were particularly interested in the physiological impact of sensory stimuli (Q2), as well as elucidating what particular aspects of stimuli caused it to be problematic or enjoyable (Q3). The final question (Q4) was constructed with a view to developing a method of ‘auditing’ an environment by determining its negative aspects and ameliorating them. The group was asked the following questions during the course of the discussion:

1. Do you feel more/less sensitive to your environment than other people seem to?
2. Do you ever have physical reactions to sensory stimuli?
3. Are there particular aspects of stimuli that make it particularly difficult or enjoyable for you?
4. What would you say are the most problematic a) visual, b) auditory and c) olfactory aspects of an environment? Can you describe why?

Ethical Considerations

The Faculty Ethical sub-committee of the University of Glasgow granted ethical permission for the study prior to recruitment commencing. Initially, contact was made with

management at a local company that employs individuals with clinical diagnoses of ASD. Thereafter, the authors met with two members of staff, where the possibility of running a focus group was discussed. It was decided that the staff at the company would be invited to participate by the Training Manager of the company, who was already known to them. We briefed her about the aim of the study and the importance of highlighting that participation was voluntary. She provided potential participants with information about the study. The decision was made to use a gate-keeper to ensure that potential participants felt no undue pressure to participate. The moderator of the focus group was the first author, who had previous experience in conducting focus groups with both adults and children. All participants were informed that the topic of the focus group would be on sensory issues and it was stressed that they would be free to leave the study at any time. All of the participants indicated that they had experienced unusual sensory perception and therefore were interested in discussing it further. Seven individuals agreed to participate, although one was not able to take part on the day chosen. This sample represented more than 50% of the full-time staff members with a diagnosis of ASD within the company.

On the day of the study, all participants were informed that they were able to leave the study at any time, without having to give a reason. They were also told that, although the data may be used for publication in journal articles or at conferences, they would not be identifiable as the transcript would be anonymised prior to analysis. All names contained within this article are pseudonyms. The participants agreed to take part in the study and signed consent forms to give their informed consent. One participant asked for clarification that data could be redacted from the transcript if necessary, which was confirmed. However, none of the participants contacted the experimenter after the study to ask for this.

*Increasing rigour**Inter-rater reliability*

AR was the sole coder for these data. However, in an effort to establish reliability, certain steps were carried out. Codes were developed by AR, who discussed them with DS as coding developed. Thereafter, AR coded the full transcript and DS coded 20% of the transcript. A Kappa Coefficient of .800 was obtained for the section of the transcript coded by both authors, which indicates a high level of agreement. In addition, intra-rater reliability was obtained (.969) for 20% of the transcript (where AR coded the transcript twice, one month apart).

Verbatim accounts

In an effort to increase the rigour of these findings, data are presented verbatim from the accounts that we received. This is a recognized method of increasing rigour of qualitative analysis (Whittemore, Chase, & Mandle, 2001).

Data Analysis

An inductive approach was deemed most appropriate for this study, as the overarching aim was to discover more about the lived experience of people with ASD, focusing on sensory experiences. We analysed the data using a general inductive qualitative approach (Thomas, 2006), in which the primary mode of analysis is the development of categories, and the outcome is the generation of key themes. This process is described as follows:

1. Preparing the raw files for analysis (e.g., transcribing using a standard template).
2. Close reading of the data in order to become familiar with the contents. At this point, the evaluator should gain an understanding of the main patterns that are present in the data.
3. Creation of categories. Lower level categories and codes are derived from repeated readings of the data and upper level themes are generated which explain the

underlying categories. For example, some of the codes represented unpleasant physical responses to stimuli (e.g., pain, headaches, nausea), which then formed a category of ‘uncomfortable physical responses’.

4. Continuing revision and refinement of category system. Within each category, data are explored for new insights and contradictory evidence. Quotations that convey the core theme are selected. Categories that overlap may be combined under a super-ordinate category. Overall themes were constructed based on the categories (e.g., ‘Physical responses’ was formed from the categories of ‘uncomfortable physical responses’ and ‘enjoyable physical responses’).

Results

The discussion generated by the group detailed the sensory experiences of individuals with a diagnosis of ASD. Four main themes emerged from these data: particular aspects of stimuli, control over stimuli, the impact of emotions and mental states, and physical responses to stimuli. Analysis of the data showed that all of the participants in the focus group reported experiencing negative as well as positive interactions with certain perceptual stimuli, which often resulted in strong physical or emotional reactions. This could either be a difficult experience, which resulted in negative emotions and physical reactions, or a positive experience, which resulted in enjoyment or comfort.

After the coding process was completed, it became apparent that the main themes interacted with each other in slightly different ways depending on whether positive or negative sensory experiences were being discussed. In order to illustrate this, an overview of ‘uncomfortable sensory experiences’ is depicted in Figure 1, with ‘enjoyable sensory experiences’ represented in Figure 2.

Figure 1

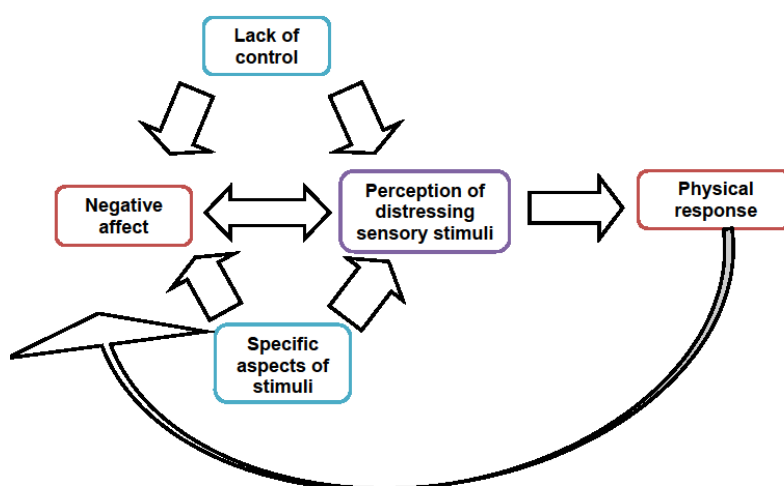
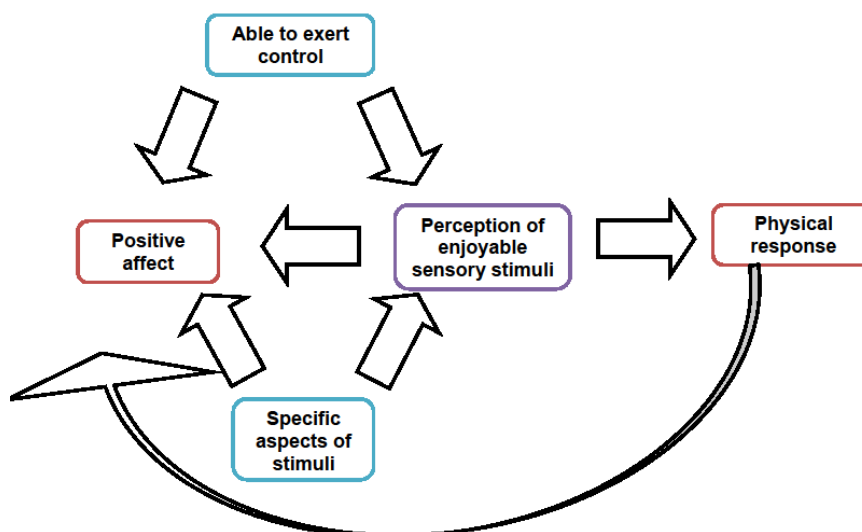


Figure 2



The discussion around negative sensory experiences mainly focused on visual, auditory and olfactory stimuli, although there were also descriptions of certain gustatory and tactile stimuli that were unpleasant to interact with. This difference makes sense, as gustatory and tactile stimuli would need direct skin contact in order to be perceived (meaning they may be easier to avoid), whereas visual, auditory and olfactory stimuli are perceived from a distance. For enjoyable experiences, the majority of the discussion centred on the auditory and tactile domains, with a particular focus on music.

The participants engaged in discussion about the control of a stimulus, and came to the conclusion that presence or absence of control can affect whether perception of it is positive or negative. Furthermore, emotions appeared to have an interesting role in perception of stimuli – like positive and negative physical responses, enjoyable and uncomfortable emotional states were often a result of interacting with problematic stimuli. However, unlike physical responses, emotions also seemed to play a role in shaping *how* a stimulus is perceived, but this was only apparent in the data for negative experiences.

Theme 1: Specific aspects of stimuli

The participants disclosed that, most often, it was the particular qualities that a stimulus possessed that had a large impact on how it was perceived. Specific aspects of stimuli that contributed to uncomfortable experiences were reported across four different sensory domains (visual, auditory, olfactory, tactile) whereas for positive experiences, they were only reported for the auditory and tactile domains.

Visual stimuli

For visual stimuli, the intensity of a light often had a discernible impact on whether response was uncomfortable. Bright lights were often cited as problematic, with participants stressing that they preferred “dullness or darkness” and that “bright light becomes very uncomfortable”. Moreover, the type of lighting used in environments was deemed very

important, with natural lighting preferable to fluorescent light (“my eyes have struggled in sort of like fluorescent light or unnatural light ... that sort of stimulus becomes painful after a while”). Chris also mentioned low flicker rates in lights, specifying that once he had noticed flicker, he found it hard to divert his attention (“I do notice flicker ... in things and I tend to have a focus on it”).

Furthermore, strong colours appeared to be an issue with certain members of the focus group, even affecting the colours used in the signs of the working environment: “I remember the issue we had with the signage in here and ... certain colours would hurt, s- so red was a no-no in here”. Patterns were also difficult for some members of staff, with Chris recalling an incident where he was unable to process the repeated pattern of items in a shop (“I have the experience still to this day of standing in the shop staring at things for about five minutes ... it’s the kind of structure of the shelves and repeated things, it becomes too much and I just stop being able to process any of it”). Matthew also mentioned having difficulty with certain patterns: “[I have problems with] maybe one of those mats ... with zillions of these metal strips like the station – it’s like an optical illusion”. Lastly, rapid change of either intensity (“when I come out of this building, I’ve got to put my head down for a minute for my eyes to adjust to the light”) or type of lighting (“if you go from here into natural light – that’s another [problem] too”) caused issues for the participants in our sample.

Auditory stimuli

Certain sounds were also a problem for the group, with particularly loud ones sometimes causing pain (“loud noise can bother me quite a lot and it can feel painful”). However, it should be noted that noises with low intensity could also cause discomfort. Greg mentioned that certain noises annoyed him (“Small noises annoy me, like breathing, crunching food or ... someone whistling ... it makes me ratty”), whereas Matthew felt that noise was often a distraction, particularly when working (“what anyone else might ...

consider minor or trivial ... like someone's music, like quite quietly ... any noise can be a distraction for me if I'm trying to concentrate").

There was also the suggestion that a mixture of competing sounds could be an issue. Sarah recalled a period where she worked in a call centre, which was particularly difficult:

The job I had before this one ... was [in] an open plan office where they played five different radios in the same office ... and then you would have people coming in and out ... by the end of each day ... I was literally sitting with my head on my desk.

The frequency of noises was also an issue; with particularly high and low frequency sounds deemed the most uncomfortable. Bill described the whirring of the computer fan and the sound of a vacuum as being uncomfortable for him: "the fan whirring in a computer ... that particular frequency can be annoying, or a Hoover ... I couldn't stand the noise of that".

Most of the participants discussed how much they enjoyed listening to music. Some particular aspects of auditory stimuli that increased enjoyment were discussed during the focus group. In particular, loud music was perceived as enjoyable. Jack discussed the positive effect that loud music has on him ("I like loud music and stuff like that really helps calm me down"), while Matthew specified that he enjoys loud music, but only of his choosing ("I like loud music, if it's my choice of music ... whether it's Mozart or ... something more rock or pop-py – if I've chosen it then I like it loud and if it's not my choice then I want rid").

Olfactory stimuli

For olfactory stimuli, intensity appeared to be the quality that was most likely to affect whether perception was uncomfortable. Greg and Chris described their reactions to a change in disinfectant gel made available in the bathrooms: "they've got a new hand gel in the loo ... and I just couldn't use it because it was just so overpowering" and "the same hand gel – I was noticing it for two days afterwards ... I've stopped using it as well". Moreover, the ability to

adapt to olfactory stimuli was reportedly diminished in our sample (“the smell of food ... I don’t get used to it while I’m around it”). Lastly, Matthew indicated certain smells could have an impact socially, as his aversion to cigarette smoke was so overwhelming that he was unable to visit certain relatives unless it was a very special occasion: “my biggest issue ... is smoking – I’ve got one relative in particular ... I won’t even visit her unless there’s a really good reason for it”.

Tactile stimuli

Chris mentioned that people lightly brushing past him could cause an adverse reaction (“people brushing past me ... it’s like pain mixed with panic ... and I can become quite aggravated because of it”). Sarah also mentioned that being hugged caused her physical pain (“[with] light hugs ... it gets to the point where my body tenses to the point of being painful”). However, the majority of examples of tactile discomfort were to do with eating certain textures of food. Both Jack (“I can’t eat whelks and mussels ... because, like, they burst in your mouth”) and Sarah (“I’ve got to sort of burst [peas and grapes] a little before I eat them because anything bursting ... I feel like anything ... pop[ping] ... in my mouth will make me feel physically sick”) disclosed that the sensation of popping in the mouth was uncomfortable. Lastly, the mixture of textures was an issue for many people in the group, with many having to eat different foods consecutively (“about mixing your textures, you find you have to eat one, you know, after another”) and experiencing nausea whenever textures were mixed (“there are other textures that, if they were mixed ... the sensation makes me want to feel physically sick”).

When it comes to pleasurable tactile sensations, cold, smooth surfaces seemed to be the most enjoyable for the participants. Chris described how he sought out cool wooden or metal surfaces: “Especially as a young child [but] still now as well ... I used to put my hand underneath chairs and stroke the metal bits on benches”. Sarah depicted how she loved the

smooth, cool sensation of tiles from a young age. In fact, she reported that they had helped her fall asleep as a child: “the basement had these sort of slate tiles ... [which] were always cool and always very smooth and if I was having trouble sleeping [my parents] would take me to the basement ... because I’d go out like a light”.

Theme 2: Control over stimuli/environment

One consistently arising point during the focus group was that of control over sensory input or the sensory aspects of the environment. The participants stressed that a lack of control altered the effect that a sensory stimulus could have. For example, Bill discussed his experiences with control over tactile stimuli:

One of the themes I’ve noticed come up quite a lot is control, for people, and that seems to matter. If they have control over the sensory input then it’s much less distressing, and I find that’s quite true with touch. If it’s a surprise, or if I don’t feel control over it, for example if somebody’s bigger and stronger, then the touch ... [is] more unsettling than if we’ve got a feeling of control.

In this example, Bill highlights that the discomfort he feels from the sensation of being touched is much less when he has control over it. Two examples that he gave for this were being the ‘stronger’ person in a hug, or being aware when someone was going to touch him.

The concept of control over sensory stimuli was important to other members of the focus group. Sarah discussed the need to be self-aware and to take precautions when interacting with potentially uncomfortable stimuli: “I’m going to see Skrillex on Saturday night, and that’s really loud dubstep with really high frequencies and really low frequencies, but I have earplugs which take out the high and the low frequencies, so I can stand it”. Sarah would only be able to attend the concert by exerting control over her sensory environment, which she did by wearing specific earplugs that acted as a type of band-pass filter.

Chris mentioned that he enjoyed working in an environment where staff were encouraged to discuss their sensory needs with management: “I find it very reassuring, even if it’s not complete control ... that it’s OK to say to people, or to even discuss [changing the environment]”. He also mentioned the relief at being allowed to alter the environment in the designated ‘chill out room’:

In the chill out room ... I find it quite comforting ... that in there it’s OK to touch the lights and stuff, because in another situation, it would make me more stressed out – the fact that I was doing something I wasn’t supposed to be.

The data from the focus group showed that the participants really valued the opportunity to adapt their surroundings and that this ethos had positive effects, both personally (“the idea that it’s OK in this environment ... to talk about [your sensory needs] ... is very comforting”) and professionally (“with that kind of provision I actually got a lot more work done than I would have imagined was possible”). Chris specified that being free to listen to music in the workplace by using earphones had reduced the sensory stress that he experiences from the environment: “the provision to be able to listen to music ... has a huge ability to kind of remove stress from the environment”.

Theme 3: Mental states and emotions

The participants in the group reported that uncomfortable mental states and emotions could both affect and be affected by sensory stimuli. This was in contrast to enjoyable mental states and emotions, which was affected by, but did not reportedly impact upon perception of sensory stimuli. Sarah disclosed that anxiety could impact on whether she was able to enter a busy environment: “if I was very anxious before going into that gig, and you know, if I was already having a pretty bad ... sensory day, then I wouldn’t be able to walk into the place”, as it made her more sensitive to the sensory stimuli in the environment. Conversely, Chris described how being anxious or upset meant he became unable to process sensory stimuli at

all: “I’ve had the experience of being in bad situations where I was ... distraught ... [and I] actually accidentally hurt myself, like standing on ... glass and not noting for at least twenty minutes that I was bleeding”.

Moreover, some participants disclosed experiences where the sensory stimuli itself caused a strong emotional reaction. Chris discussed how the temperature of an environment was important for him: “if an environment’s too warm, that would ... be like the worst thing – I lose all ability to focus [and] become very, very agitated”. Moreover, Sarah discussed the strong reaction she would have to a certain brand of tobacco (“a friend of my grandfather ... smoked Golden Virginia and it would frighten me – I would run away screaming”) and the effect that smells could have on her perception of a person (“I associated a person by their smell ... they could be the nicest person in the world but if I didn’t like how they smelled, they were evil to me”).

The participants in the focus group also described the pleasure they received from interacting with certain sensory stimuli. Sarah mentioned that she enjoyed the whole process of eating a particular type of chocolate biscuit, predominantly because of the wrappers: “I liked the sensation of pressing the tinfoil into the KitKat ... and... tearing the paper open ... it was a very tactile pleasure”. Predominantly, the sample reported feeling a sense of comfort when interacting with sensory stimuli. Chris and Sarah both described deriving comfort from small sections of songs or certain sounds, even using software to loop the sections in order to be able to listen again and again (“I would just keep repeating ... the same 10 seconds of a song ... it is something to comfort me’ and ‘I would use ... music software ... to isolate that sound – just have that looping constantly and that would bring great comfort”).

As mentioned previously, the pattern observed in the negative experiences (i.e., that mood and emotions shape sensory perception) did not emerge in the discussion of positive sensory experiences. However, the ability to manipulate emotions, particularly by using

music, was discussed at length. Greg reported that a certain piece was able to calm him down when stressed: “I’ll listen to classical music if I want to be calm or I want to be peaceful ... other music, you’ll learn if you want to be happy ... playing Vivaldi’s Four Seasons ... is the only way [for me] to sort of calm down in certain situations”. In addition, Jack discussed how he uses music playlists to alter his emotional state: “I can almost manipulate my responses to the sound ... and sort of, you know, program that”.

Theme 4: Physical responses

All participants in the focus group described experiencing some sort of physical discomfort from sensory stimuli at some point in their lives. The majority of examples were related to pain in the visual, auditory and olfactory domains. Chris described feeling pain when he smelled certain scents (“bad smells feel quite painful as well ... I always just assumed that’s just how they are”). Headaches and migraines were commonly reported for specific types of lighting (“I actually get severe migraines because of light” and “strip lighting ... that can immediately ... hurt a lot”). Moreover, loud noise (“loud noise can bother me quite a lot and it can feel painful”) and certain frequencies (“high-frequency noises and low-frequency noises tend to really hurt me”) were reported to cause physical discomfort. In addition, some participants mentioned that a sensory stimulus could elicit nausea, although this reaction appeared restricted to interaction with foodstuffs: “if ... [there’s] a strong kind of sensory smell of a food ... I couldn’t even think about eating it” and “[if] textures ... were mixed ... the sensation makes me want to feel physically sick”.

The participants also discussed positive physical responses to sensory stimuli, which typically involved relaxation and aiding the onset of sleep. Sarah mentioned that her eyes feel as if they noticeably relax when she goes into a room with natural lighting: “I can physically feel my eyeballs straining right now, because of the light in this room – but as soon as I go into my office, you know, I can feel them almost sort of ... relaxing”. Matthew discussed that

the sound of a detuned radio would help him to sleep (“A radio not tuned to anything is a very send asleep noise for me”), whereas Chris described the sound of a vacuum as being soothing (“When I was a child my mum said the only way I could sleep was if she put the Hoover on”).

Minor themes

Adaptation

One of the other themes that emerged during the focus group concerned adaptation. Participants reported that they did not habituate as readily to stimuli as others appeared to. Chris described noticing that other people seemed to be more able to adapt to stimuli: “I don’t get used to a smell very quickly – I notice other people ... if they mention a bad smell they seem to forget about it – it doesn’t seem to die down in the same way [for me]”. He also described that it took him weeks to get used to the smells in a new environment: “It would have to be weeks ... before I would get used to the smell of a place”.

Single-channel processing

Many of the participants described experiencing single-channel processing, where the sensory channels appear to stop processing information to the exclusion of one modality. Matthew reported that small noises could ‘shut off’ his other senses in a discussion with Sarah:

Sarah: “small noises annoy me, like breathing or crunching food or, you know, someone whistling (...) it makes me ratty as well because – ”

Matthew: “it shuts off your other senses, in a certain respect”.

Matthew indicated that when his attention is diverted to an annoying stimulus, he is less likely to notice the sensations from his other senses.

Chris reported that this often happened to him and he would often use it in a positive way, to deal with difficult sensory situations. He found that he found it much easier to cope

with crowds at a gig than in other situations, because he was able to concentrate on the music being played:

... it's the same with gigs, I haven't been in a while, but I used to do that. In any other crowded environment I'd have been extremely anxious, but that kind of – the fact I'm engaging one sense kind of dulls everything else out. [The crowd] stops being an issue entirely.

This shows that Chris attributes his problems with crowds to be, at least in part, a result of his sensory sensitivities. By engaging in single-channel processing, he feels better able to cope with large numbers of people. He also said using headphones in a busy street could be helpful: “it's like tunnel vision with one sense at a time ... I have to listen to music on my headphones when I'm in busy streets ... and it has to be loud”.

Coping Strategies

The participants also indicated that, when sensory problems arose, they often made certain adjustments in order to be able to interact with them. Greg described having to eat food consecutively, so that the textures and tastes of the food would not mix in his mouth: “when I used to be smaller ... you'd work your way around the plate, you'd never mix textures or anything like that. It's not until, what, about five, six years ago that I'll actually put meat with a veg with potato”. Sarah mentioned something similar: “going on from what Greg was saying... you find you have to eat one, you know, one after the other so that your ... mouth isn't basically fighting to process the tastes at the same time”. Eating foods one at a time appears to be a strategy used by some individuals with ASD to deal with the myriad of textures and tastes that can be present during meals.

There were other examples which highlighted that the participants in the focus group readily made changes to compensate for their strong sensory aversions. Sarah described how she disliked the smell of her mother-in-law, because of the deodorant she wore, and the steps

she was taking to overcome this: “I don’t like how my mother-in-law smells ... I’ve tried to make myself associate with her ... she uses a certain type of deodorant and I’m trying to force myself to accept that smell by trying to use the deodorant myself”. In addition, Bill mentioned that he found certain frequencies of noise to be particularly irritating, and he would shut the door to try and block them out: “it used to be I’d always shut the door when the Hoover was going. I couldn’t stand the ... noise of that”. As previously reported, Sarah described finding high and low frequencies particularly distressing, and had to resort to using earplugs.

Discussion

This study reports the sensory experiences of a group of adults with a diagnosis of ASD. By extracting the most common themes from the data, we were able to build a picture of the sensory experiences that are most problematic and most enjoyable for our participants, as well as the factors that are perceived to affect them. Four main themes emerged from the data: a) the importance of particular aspects of stimuli in their perception, b) the importance of having control over stimuli, c) how emotions/mental states could impact/be impacted by sensory stimuli and d) physical responses to stimuli. The ways in which the main themes interacted with each other is visually depicted in Figure 1 (uncomfortable) and Figure 2 (enjoyable). Other important findings from these data will also be discussed.

The findings contained within this paper add to the extant literature in a variety of ways. Firstly, although other studies report similar themes of control and avoidance (Dickie et al., 2009; Ashburner, Bennett, Rodger, & Ziviani, 2013) and uncomfortable physical responses (Kirby et al., 2014), both of these studies recruited a sample of children, rather than adults. There is some evidence that sensory reactivity may change as we age (Kern et al., 2007), therefore it is important to ascertain that these aspects of sensory experience are important to adults with ASD as well as children. Secondly, although Dickie et al. (2009) also

reported the specific aspects of stimuli that parents reported were problematic to their children, we provide a more in-depth overview from a first-hand rather than second-hand perspective. Finally, our participants also discussed adaptation to stimuli in depth, which has not been covered in detail elsewhere, to our knowledge.

For our participants, the most impactful aspect of interacting with stimuli was the concept of control. The participants were all in agreement that control was extremely important, and it was a theme which was discussed openly within the group: “one of the themes I’ve noticed come up a lot is control ... if they’ve got control over the sensory stimulus then it’s much less distressing”. Dickie et al. (2009) also found that uncontrollable stimuli were more distressing for both children with ASD and controls than sensory stimuli that could be induced and terminated by the children themselves, while Ashburner et al. (2013) also highlighted it as an important theme in their qualitative study. It should be noted that Blakemore et al. (2006) found that individuals with AS rated self-controlled touch to be just as intense as experimenter-controlled touch, compared to controls, who rated self-controlled touch as less intense. However, the nature of the touch was not distressing, so it may be that control is most important with negative sensory experiences.

Our participants described the extremely debilitating effect that negative sensory experiences could have. Physical responses to sensory stimuli varied from nausea (“[if there’s a] strong kind of sensory smell of a food ... it makes me feel physically sick”) and physical pain (“[with] light hugs ... it gets to the point where my body tenses to the point of being painful”) to becoming immobile (“[with] high-frequency and low-frequency noises ... I’ll just become like a statue”). The description of sensory stimuli as being painful was also found in the qualitative studies mentioned previously (Ashburner et al., 2013; Dickie et al., 2009; Jones et al., 2003; Kirby et al., 2014; Smith & Sharp, 2013). For the participants in these studies too, it appeared that particularly intense stimuli, or stimuli with a particular

quality (e.g., certain frequency content or texture), was very problematic. Our participants also discussed positive physiological responses to sensory stimuli, which often resulted in relaxation.

In addition, the participants in our study described experiencing emotional discomfort when interacting with certain stimuli (“if an environment’s too warm ... I become very, very agitated”). It should be noted that, in the sample, negative emotional states (e.g., anxiety and distress) reportedly affected perception in some way, either decreasing tolerance for sensory stimulation (“if I was very anxious before going into that gig, and if, you know, I was already ... having a bad sensory day, then I wouldn’t be able to walk in”) or diminishing the ability to perceive sensory stimuli that causes pain (“when I’m particularly anxious, I don’t feel pain at all”). It is particularly important to note that the same relationship was not observed for positive sensory experiences; there was no evidence in the data that experiencing positive emotions would impact positively on sensory experiences. These descriptions concur with the literature; there is evidence that threat and anxiety can affect some aspects of visual perception in the general population (Laretzaki, Plainis, Argyropoulos, Pallikaris, & Bitsios, 2010). Furthermore, it has been established that emotions can affect pain perception (Malow, 1981). In Malow’s study, participants became less likely to *report* the pain they were experiencing as their anxiety increased, despite no significant difference in pain threshold. This concurs with Chris’ experience, as once his injury was pointed out to him, he became aware of the sensation of pain (“I’ve actually accidentally hurt myself, standing on ... glass, and not noting for at least 20 minutes that I was bleeding, until somebody pointed it out”).

Two participants in our sample reported having a difficulty with certain patterns. Matthew reported that he disliked grid-like patterns with “zillions of [...] metal strips”. Chris reported one incident where he had become immobile as he was unable to process the pattern of products in a shop. ‘Visual stress’ refers to the discomfort experienced when viewing

certain patterns (e.g., stripes) that are unlike those that occur in nature (Penacchio & Wilkins, 2015). It is possible that the aversive responses to patterns described by these participants could be a result of visual stress. Although Ludlow, Wilkins and Heaton (2006) have studied the effect of self-selected colour overlays on reading efficacy in children with autism, there has been no research published on the relationship between ASD and the more general concept of visual stress.

The participants described manipulating their emotional and physical states with certain sensory stimuli, often using it as a way to calm themselves down. The most common method of doing this was to play music. The use of music as a tool to soothe agitated individuals has been observed in people with dementia (Janata, 2012; McDermott, Orrell, & Ridder 2014) as well as individuals who have experienced a stroke (Forsblom, Latinen, Särkämö, & Tervaniemi, 2009). Furthermore, Stoudenmire (1975) found that music could have a significant effect on situational anxiety in the general population.

The participants also described being fascinated by certain stimuli and reported great pleasure in interactions with them (i.e., being a source of enjoyment rather than being used as a tool to manage stress). Again, this has been found in previous research (Dickie et al., 2009; Jones et al., 2003; Smith & Sharp, 2013). Smith and Sharp (2013) conducted interviews with adults who had a diagnosis of AS. Using a grounded theory approach, they developed a model to explain how sensory experiences can be positive (i.e., fascination) or negative (i.e., isolation). Dickie et al. (2009) reported that one parent described how their child derived pleasure from movement “he likes to jump. So he jumps a lot, and he seems to get pleasure out of that”. In our sample, the majority of pleasurable experiences were involved with touch. Sarah described how she felt when touching cool metal: “I like touching metal a lot ... I love smooth metal – like, cold smooth metal is like, just amazing”. One of the major themes to emerge from Jones et al. (2003)’s research was that sensory experiences could be highly

enjoyable. One of their participants, Jane, described how enjoyable sensory experiences seemed heightened for her, compared to individuals without autism: “All things are heightened for me, so what a regular person would be tickled with pleasure over, I’ll be totally ecstatic”. The concept that both negative and positive responses to sensory stimuli are heightened in ASD was also discussed in our group, with the consensus being that the experience of sensory stimuli for people with ASD is different from typically developing individuals: “the main things that have bothered me throughout my ... life ... make more sense now (with) the diagnosis, but [I already knew] that [the sensory issues] were different from other people ... they were more problematic for me”.

Adaptation to sensory stimuli was also discussed within the group, with some of the participants reporting that they did not feel they habituated to stimuli as quickly as others appeared to. This was particularly evident when discussing smells, with one participant mentioning that he could still smell alcohol disinfectant gel for days after he uses it. However, Tavassoli and Baron-Cohen (2012) found no difference in the adaptation of individuals with ASD and typically developing (TD) controls to olfactory stimuli. Despite this, findings for olfactory processing in ASD have been mixed (Bennetto, Kuschner, & Hyman, 2007; Dudova et al., 2011; May et al., 2011; Suzuki, Critchley, Rowe, Howlin, & Murphy, 2003; Tavassoli & Baron-Cohen, 2012), so further investigation is warranted, particularly as unusual adaptation to stimuli has been observed in the visual (Pellicano, Jeffery, Burr, & Rhodes, 2007) and tactile (Tommerdahl, Tannan, Cascio, Baranek, & Whitsel, 2007) domains.

Furthermore, some participants described a phenomenon where, once fixated on a strong stimulus, they became unable to consciously process information in the other sensory domains. This phenomenon was also discussed in Jones et al. (2003)’s paper. One of their participants, James, had developed this skill in order to cope with lots of stimuli in class. He

was able to filter out all non-auditory information, which enhanced his ability to maintain concentration. In addition this skill was tremendously enjoyable, as he was able to replay enjoyable experiences verbatim. The main difference between the experiences of our participants and James is that the latter appears to have developed the ability to turn it on and off at will, whereas for Matthew and Chris in our sample, it seems to be uncontrollable.

Finally, the participants described using certain coping strategies to cope with aversive sensory stimuli. These included eating foods a certain way (e.g., one after the other), wearing earplugs which filter out high and low frequencies, having to pop the skins of certain foods before eating and wearing deodorant in order to try and become habituated to the smell. This shows that the adults in our focus group have developed strategies for certain issues, and may go some way towards explaining some of the unusual behaviours exhibited by those with ASD. Difficulties with food appear to be commonplace in individuals with ASD (Ahearn, Castine, Nault, & Green, 2001; Schreck & Williams, 2006), and it may be that similar issues underlie unusual eating behaviours in younger children. Our participants relayed that some of them still ate food sequentially, even as adults. In fact, the oldest participant in the group (Greg, at 51 years 6.3 months of age), disclosed that he had only started to eat foods together 5-6 years previously. It is well known that the senses of taste and smell diminish as we age (Schiffman, 1997), so one explanation for Greg being able to mix foods now may have been that his hyper-sensitivity to food has reduced as he has aged.

Limitations

One potential limitation of the study is that all the participants knew each other. There is often an expectation, which appears to stem from their market research origins, that focus groups should consist of strangers (Morgan, 1998), although the value of using pre-existing groups is highlighted in the literature (e.g., Kitzinger, 1994; 1995). We argue that prior

relationships were beneficial to the study, as it meant that participants were comfortable with each other and enthusiastic about participating.

Another possible limitation was that our sample exclusively consisted of extremely able individuals. It is possible that sensory processing may be qualitatively different in highly able individuals with ASD compared with those who, in the language of DSM-5, require “very substantial support”. Studies investigating whether there appears to be a difference between such subgroups of ASD have demonstrated that there do for children (Kern et al., 2007; Zachor & Ben-Itzhak, 2014), but not for adolescents and adults (Kern et al., 2007).

In addition, there are some methodological limitations that should be addressed. In particular, it is likely that the rates of agreement for the codes (as reported in the methods section) are inflated as AR (the primary coder) developed them with limited discussion from DS (the second coder). Therefore, it is unlikely that the rates of both coders are totally independent from each other. Finally, it is a limitation that only one focus group was conducted; multiple groups are always recommended in order to aid in-depth exploration of a topic (Litosseliti, 2003). However, it should be noted that this study was one component in a larger body of work designed to elucidate the nature of sensory issues in ASD from a variety of perspectives.

Practical implications of the findings

The data from the focus group shows that low-impact environments are important, and that modification of the environment could potentially have a positive impact on the productivity and well-being of individuals with ASD. As such, taking measures to modify the environment could make accessibility easier for individuals with ASD, and could potentially minimise distress in uncomfortable situations. Indeed, it may be the case that small adjustments to the environment could be helpful to many people in the general population, as evidence suggests that individuals with elevated, albeit subclinical, levels of autistic traits

report atypical sensory perception (Horder, Wilson, Mendez, & Murphy, 2014; Robertson & Simmons, 2013, Uljarević et al., 2014).

Future research directions

Many years of research on sensory and perceptual processing in ASD have failed to find consistent differences between ASD and control populations in low-level perceptual functioning (see, e.g., Simmons et al, 2009). The question remains of whether this is because the experiments used to test this functioning have not been subtle enough to detect these differences, or whether the sensory issues reported by individuals like those in our sample are essentially caused, and certainly exacerbated, by other facets of ASD such as increased levels of anxiety (Smith & Sharp, 2013). This question is an important one because it influences what measures should be put in place to alleviate these difficulties. A further complication is that our previous research shows that there is potentially a large proportion of the general population who report similar difficulties (Robertson & Simmons, 2013).

It may be the case that attentional factors or affect, for example, play an important role in the modulation of sensory information. It would be particularly interesting to explore further the relationship between positively and negatively valenced emotions and sensory perception. Further research into the relationship between these factors and sensory responsiveness could help improve understanding of their impact on the sensory experiences of individuals with ASD.

Finally, one of the participants in our sample reported that he found small noises extremely irritating, which may be indicative of misophonia. Misophonia is a negative physiological and emotional reaction to sound (Bernstein, Angell, & Dehle, 2013) which has been reported in the general population. There has been some discussion of a possible relationship between misophonia and autism (Steigler & Davis, 2010), although there is little published evidence on this topic. Future research in this area may explore this to determine

whether there is a link between misophonia and autism, and if so, gain a better understanding of the nature of their relationship.

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Figure Captions

Figure 1. The aspects of a stimulus that reportedly impacted on perception (blue/dashed boxes) and the consequences of interacting with distressing sensory stimuli (red/dotted boxes). It should be noted that uncomfortable emotions were also reported to have an effect on the perception of a stimulus

Figure 2. The aspects of a stimulus that reportedly impacted on perception (blue/dashed boxes) and the consequences of interacting with enjoyable sensory stimuli (red/dotted boxes)